

# Development and Usability Testing of a Patient-based Digital Tool to Understand Early Signs of Changes in Multiple Sclerosis Symptoms and Progression: Your MS Questionnaire

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# Background

## WHY?



- Aiding the discussion of symptoms between plwMS and HCPs to detect subtle signs of disease worsening remains an unmet need. The questionnaire was developed to fulfill this gap<sup>1</sup>

## HOW?



- Your MS Questionnaire (YMSQ; [www.yourms.com](http://www.yourms.com)) was developed with input from plwMS, patient advocacy groups, and HCPs and is based on MSProDiscuss™ – a physician-completed digital tool ([www.msprodiscuss.com](http://www.msprodiscuss.com))<sup>2,3</sup>

## WHAT?



- YMSQ is a patient-completed questionnaire that asks for information on relapses, symptoms, and impacts experienced within the past 6 months
- The purpose of this questionnaire is to facilitate a discussion between HCPs and plwMS to better understand patient history, symptoms, and the impact experienced by the patient

# Objectives



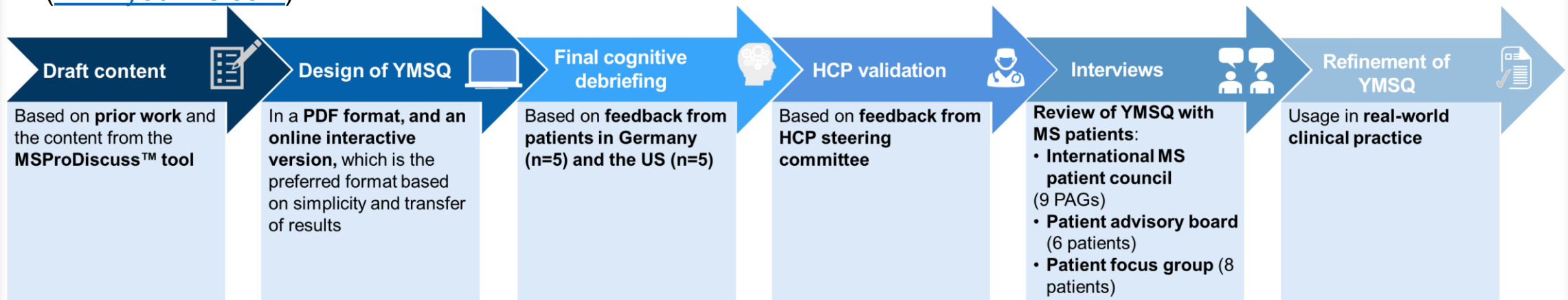
**To develop a patient-based tool, Your MS Questionnaire (YMSQ), that is completed by plwMS**

**To evaluate the usability of YMSQ in helping both plwMS and HCPs in clinical practice**

# Methods

## Development of YMSQ

- YMSQ was designed based on MSProDiscuss™ to capture the experience of plwMS regarding changes in their MS symptoms and subsequent impact on daily living over the past 6 months
- The questions were identified as relevant through qualitative and quantitative research with experienced HCPs, plwMS, and patient organizations
- YMSQ was initially developed as a paper tool; however, due to the COVID-19 pandemic and the switch to telemedicine, plwMS were also provided the option to complete an online version prior to the consultation ([www.yourms.com](http://www.yourms.com))



**YMSQ was developed using inputs from plwMS, patient organizations, and HCPs**

# Methods

Layout of PDF version of YMSQ; online version can be accessed at [www.yourms.com](http://www.yourms.com)

## Your MS

This questionnaire asks about your MS in the past 6 months, including any relapses, your symptoms and their impact on your daily life. This information will help you have a focused discussion with your doctor about your MS and any changes you have experienced over the past 6 months. If possible, ask a family member, partner or carer for help and input when completing the questionnaire.

What is your age?

Please mark one box per question to give your answer

### 1. Your MS

1.1 In the past 6 months have you had any relapses (periods of time where your symptoms were worse and then got better)? Yes  No   
Go to section 2

1.2 If yes, how many relapses? 1  2  3+

1.3 If yes, how well did you recover from your most recent relapse?  
Fully (100%)  Nearly fully (75%)  Partially (50%)  A little (25%)  Not at all (0%)

GLNS/MSCL/0391a

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### 2. Your symptoms

a) Have you experienced any of the following symptoms in the past 6 months?

		No	Yes
2.1	Problems with your vision	<input type="checkbox"/>	<input type="checkbox"/>
2.2	Muscle weakness or muscle spasms	<input type="checkbox"/>	<input type="checkbox"/>
2.3	Problems walking or getting around	<input type="checkbox"/>	<input type="checkbox"/>
2.4	Problems with coordination or balance	<input type="checkbox"/>	<input type="checkbox"/>
2.5	Pain	<input type="checkbox"/>	<input type="checkbox"/>
2.6	Numbness or tingling	<input type="checkbox"/>	<input type="checkbox"/>
2.7	Bladder control or bowel problems	<input type="checkbox"/>	<input type="checkbox"/>
2.8	Problems with your speech	<input type="checkbox"/>	<input type="checkbox"/>
2.9	Problems concentrating or remembering things	<input type="checkbox"/>	<input type="checkbox"/>
2.10	Feeling tired or fatigued	<input type="checkbox"/>	<input type="checkbox"/>

For all symptoms that you answered yes for in Q2a

		b) Did you experience these symptoms during any relapse you had in the past 6 months?				c) Did the symptoms come and go or were they there most of the time?			d) If symptoms were there most of the time...		
		No	Yes	No	Yes	Symptoms came and went		Symptoms were there most of the time	Did they get better?	Did they stay the same?	Did they get worse?
2.1		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.2		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.3		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.4		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.5		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.6		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.7		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.8		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.9		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.10		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### 3. How MS impacts your life

How much have your MS symptoms over the past 6 months affected you:

	Not at all	A little	Moderately	A lot	I can't do this because of my MS
3.1  Getting around	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.2  Washing, bathing or dressing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.3  Completing everyday tasks (for example, housework or driving)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.4  Doing hobbies or leisure activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.5  At work (paid or volunteering)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> I cannot answer Q3.5 because I do not work for reasons unrelated to my MS					
3.6 Being intimate or having sex	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.7 Emotionally (for example, feeling low, anxious or worried)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

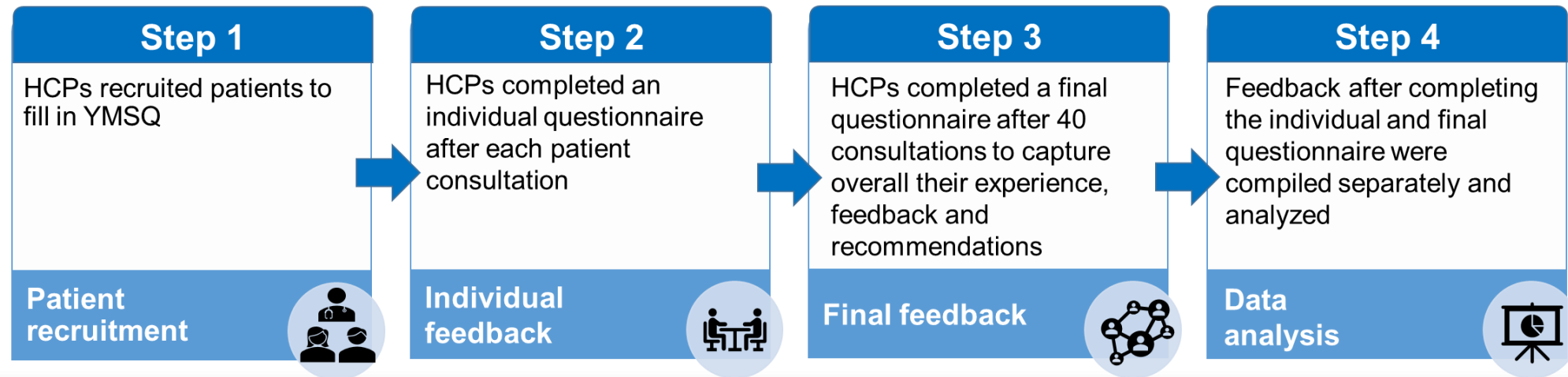
Are there any specific symptoms that you would like to focus on when you meet with your doctor? If so, please circle/mark the relevant question number(s) in this questionnaire, or write the relevant question number(s) in the box below.

User friendly, online version of YMSQ can be freely accessed at [www.yourms.com](http://www.yourms.com)

# Methods

## *YMSQ usability testing: A two-part HCP survey*

- **Individual questionnaire (15 questions):**
  - After every patient consultation, feedback was collected for usability and usefulness, comprehensibility, patient and HCP satisfaction, and usability in conjunction with MSProDiscuss™
- **Final questionnaire (15 questions):**
  - After 40 patient consultations (a minimum of 10), in-depth feedback was collected on usefulness, integration into clinical routine, and recommendations for improvement areas
- HCPs provided their response in 4 categories: strongly agree, agree, disagree, strongly disagree



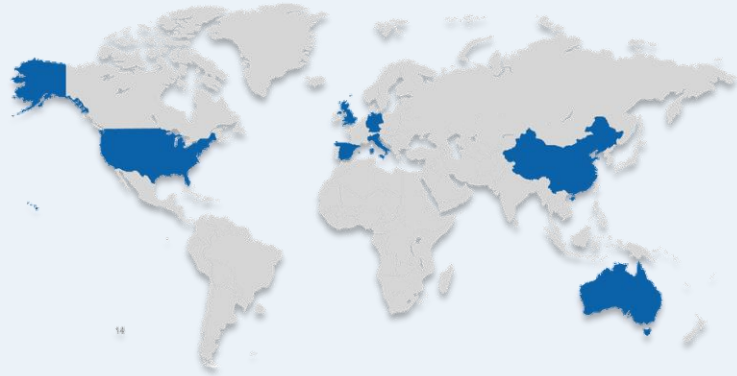
# Results

## Survey participants

Until close of usability survey (July 23, 2021)



**7 countries**



HCPs from **Australia, China, Germany, Italy, Spain, UK, and US** completed the testing



**13 HCPs**



Majority of the HCPs associated with the usability testing were from the YMSQ development steering committee



**261** MS patient consultations (83.9% RRMS)



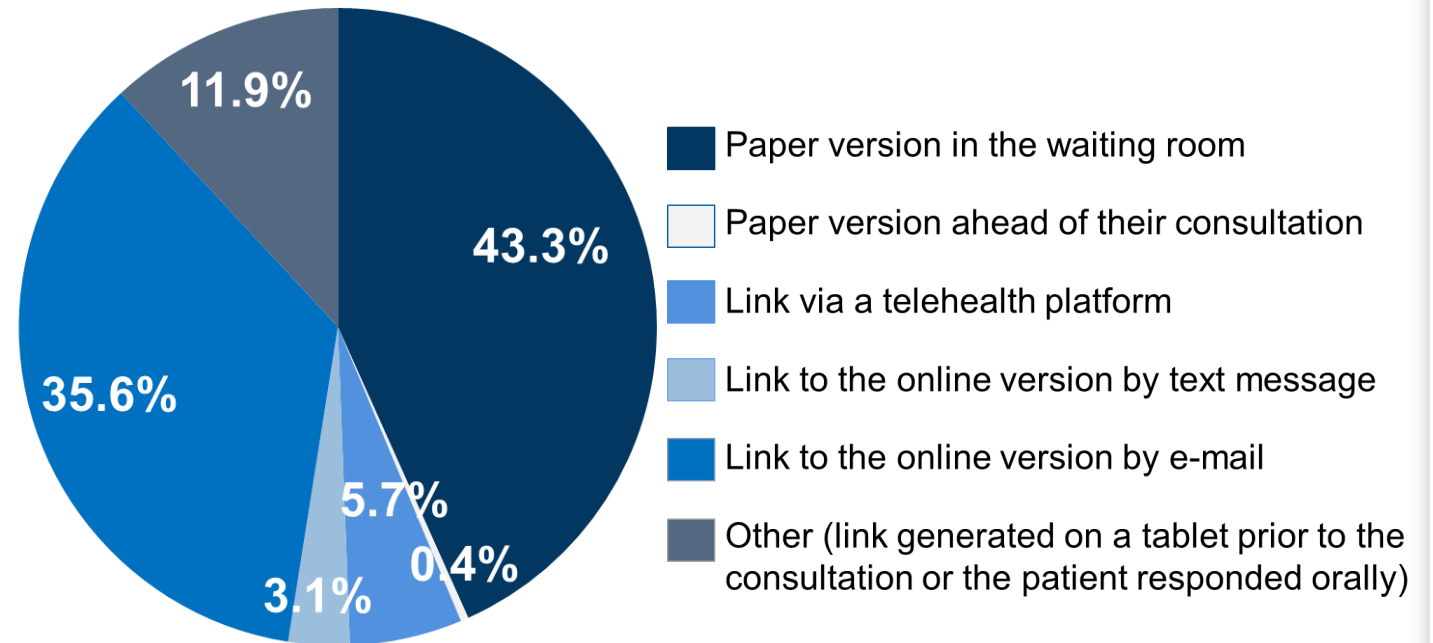
Testing is based on consultations of patient with MS where YMSQ was used



# Results

*Distribution channels for YMSQ: 36% of the patients received the digital version via email*

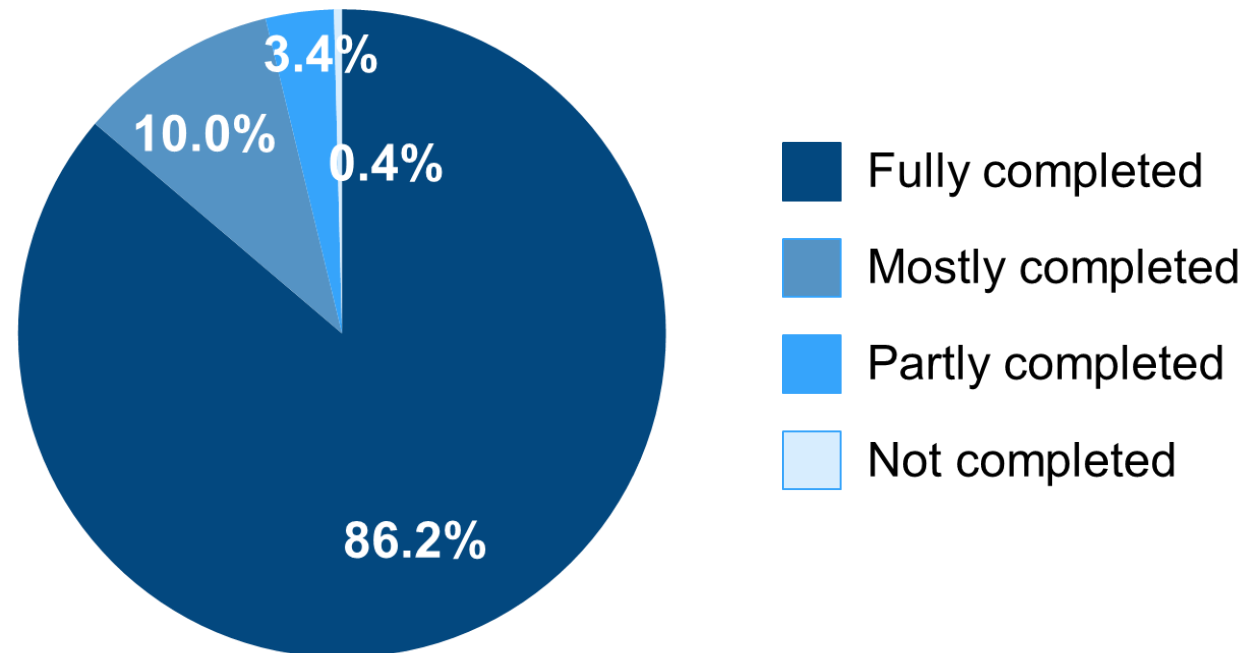
- There was interest in a digital version of the questionnaire
  - 35.6% received a link to the online version via e-mail
- 43.3% of patients received the paper version of the questionnaire in the waiting room
- Overall, 65.1% of the patients received the questionnaire on the day of their consultation



# Results

*Completion status of YMSQ\*: Majority of the questionnaires were fully completed*

- Overall, 86.2% of the questionnaires were fully completed
- Most questionnaires (85.4%) were completed alone by plwMS



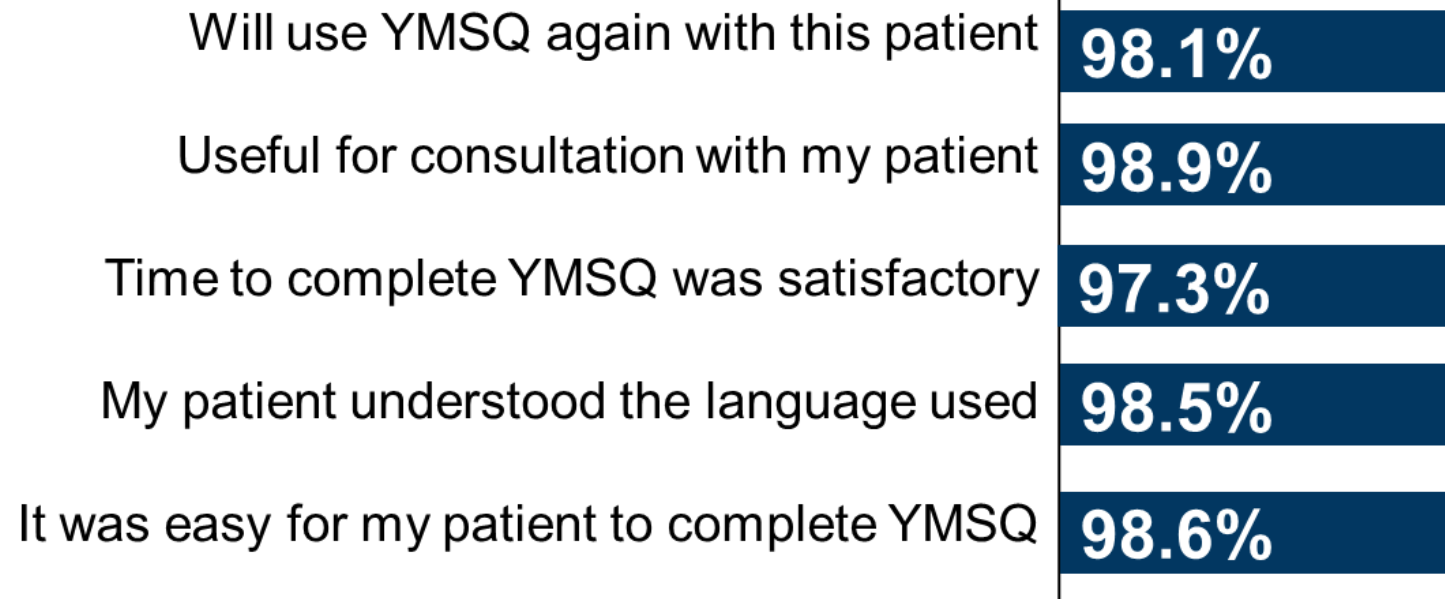
\*"Mostly" refers to >50% of the questionnaire, while "Partly" refers to <50% of the questionnaire.

MS, multiple sclerosis; plwMS, people living with MS; YMSQ, Your MS Questionnaire.

# Results

## Individual questionnaire

### HCPs' feedback based on the 261 individual questionnaires\*



- **Most HCPs agreed or strongly agreed that YMSQ was useful in their practice and was easy for plwMS to use and understand**

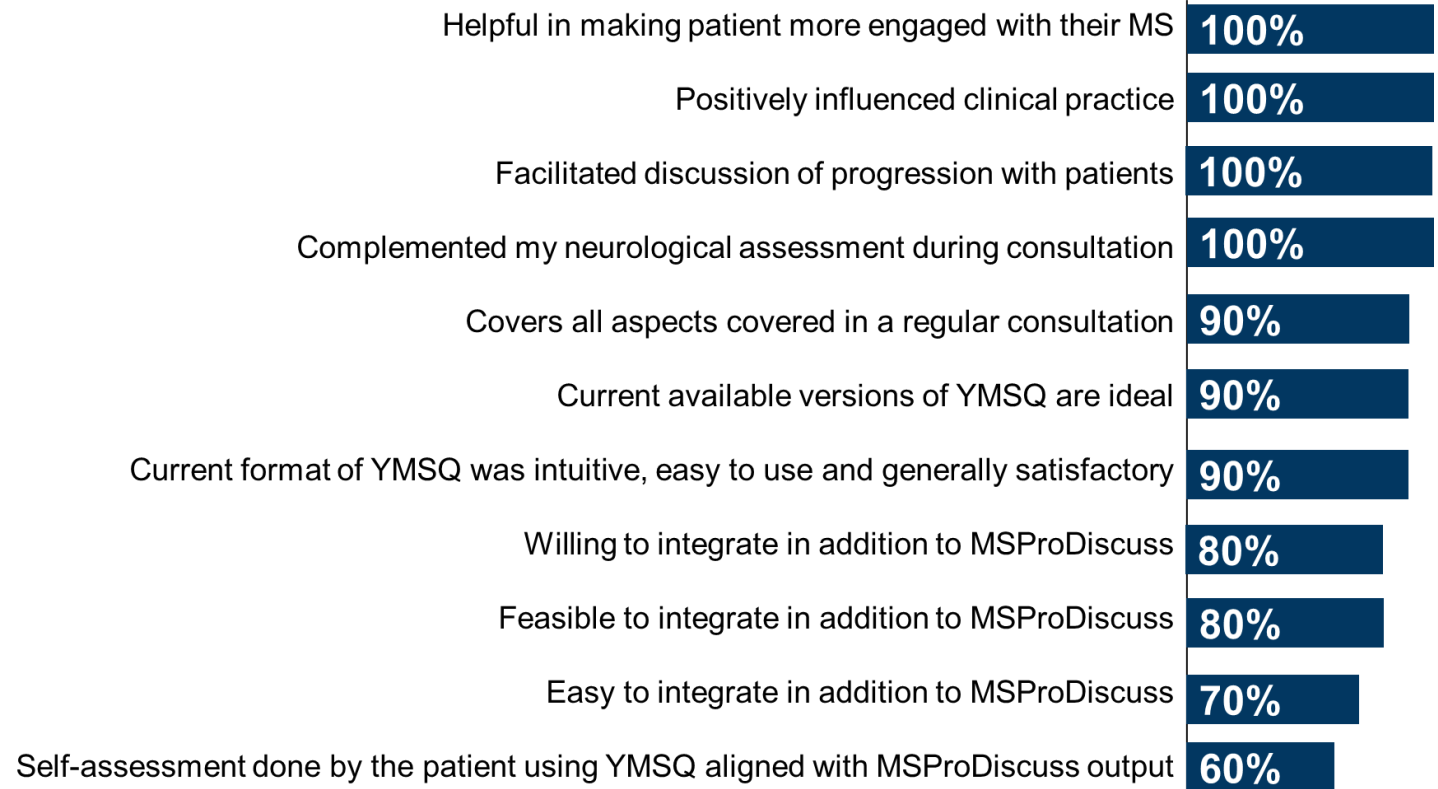
\*Data represents the responses falling under the categories "strongly agree" and "agree."  
HCP, healthcare professional; MS, multiple sclerosis; plwMS, people living with MS; YMSQ, Your MS Questionnaire.

# Results

## Final questionnaire

- Most HCPs agreed or strongly agreed that the use of YMSQ positively influenced the clinical practice; it was helpful in engaging patients with their MS
- Most HCPs (80%) were willing to integrate the YMSQ in addition to MSProDiscuss™ in routine clinical practice

### HCPs' feedback based on final questionnaires\*

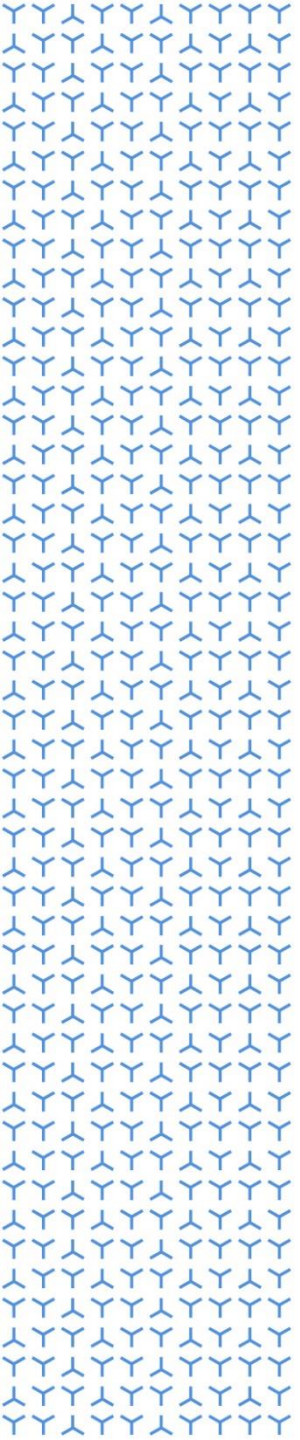


\*Data represents the responses falling under the categories "strongly agree" and "agree."  
HCP, healthcare professional; MS, multiple sclerosis; MSProDiscuss, Multiple Sclerosis Progression Discussion; YMSQ, Your MS Questionnaire.

# Conclusion

- YMSQ was developed with inputs from plwMS, patient advocacy groups, and HCPs, based on the MSProDiscuss™, a physician-completed digital tool
- YMSQ facilitates discussion between plwMS and HCPs on changes in MS symptoms and ways in which they impact daily activities within the past 6 months, enabling a holistic approach to management of patients with MS
- Based on results from the usability testing of YMSQ in real-world clinical practice, HCPs found YMSQ useful, are willing to use it again on the same patients, and plan to integrate it in routine clinical practice
- When completed before consultations, YMSQ may benefit plwMS and HCPs by enabling a better-structured conversation and a better-informed consultation, with practical uses in telemedicine

**Your MS Questionnaire is freely available online at [www.yourms.com](http://www.yourms.com)**



**Thank you**